



The purpose of this anonymous survey is to ask you, adults with NF, about your thoughts regarding participation in clinical trials. This research study will help us design clinical trials that are meaningful to you and that you would want to participate in.

Clinical trials are research studies that help determine whether new treatments are safe and improve health outcomes. Psychosocial clinical trials are a type of clinical trial that determines whether particular programs or skills can help patients and/or family members better cope with their stress, symptoms (for example: pain), and feelings to help improve general well-being and quality of life.

For this survey, we are interested in your opinions about psychosocial clinical trials. This is your chance to let us know what is important to you and how we can better serve you.

We also will ask a few questions about how coronavirus (also called COVID-19) pandemic is affecting your psychosocial health.

We value your input and we want to know your ideas!

Instructions and consent for the survey:

Completion of this survey is entirely voluntary. You have the option of not participating. You have the option to stop participating at any time or to not respond to a particular item or items. You may refuse to participate or stop participating at any time without penalty or loss of benefits to which you are otherwise entitled. There are minimal risks associated with doing the survey. These risks may include the time involved to complete the questions as well as the potential for discomfort to arise when answering questions related to social and emotional wellbeing. There are no benefits except for helping researchers design studies to help address the psychosocial concerns of individuals with NF.

THERE IS NO PERSONAL IDENTIFYING INFORMATION DATA BEING COLLECTED SO YOUR RESPONSES ARE COMPLETELY ANONYMOUS.

We will not know who participates and who does not. The responses to these survey questions will be stored in a secure database. We will do our best to make sure that these data are kept private.

If you have questions about this study, please contact Dr. Pam Wolters at woltersp@mail.nih.gov or Dr. Staci Martin at martins@mail.nih.gov. You may also contact them at 240-760-6040 if needed.

There is a total of 67 questions in the survey. It will take about 35 - 50 minutes to complete. Please allow enough time to complete the entire survey at one time because it is not possible to save the responses and then return to complete the rest of the questions later.

If you agree to participate in this anonymous research survey, please check the box.

* must provide value

I agree to participate in this research.

Submit

Resize font:


1. Do you read and understand the English language?

* must provide value

Yes

No

reset

Submit

End the survey?

You have selected an option that triggers this survey to end right now. To save your responses and end the survey, click the button below to do so. If you have selected the wrong option by accident and do not wish to leave the survey, you may click the other button below to continue, which will also remove the value of the option you just selected to allow you to enter it again and continue the survey.

End the survey now

Continue survey and undo last response

1. Do you read and understand the English language?

* must provide value

Yes

No

reset

1a. Are you 18 years of age or older and have a diagnosis of NF1, NF2, or Schwannomatosis?

* must provide value

Yes

No

reset

Please answer the questions in this survey about your experiences as an adult with NF1, NF2, or Schwannomatosis.

If you are a parent of a child with NF, we will have a separate survey for you to complete in the coming months to address the needs you and your child may have.

Submit

End the survey?

You have selected an option that triggers this survey to end right now. To save your responses and end the survey, click the button below to do so. If you have selected the wrong option by accident and do not wish to leave the survey, you may click the other button below to continue, which will also remove the value of the option you just selected to allow you to enter it again and continue the survey.

End the survey now

Continue survey and undo last response

Resize font:
⊕ | ⊞

2. What is your age?

3. What sex were you assigned at birth on your birth certificate?
 Female
 Male
reset

4. Do you identify yourself as:
 Female
 Male
 Transgender female
 Transgender male
 Non-binary
 My identity is not listed
reset

4a. Please specify.
Expand

5. Country of residence:
 USA
 Other
reset

5a. State of residence:

5b. Please specify.

6. What is your race?
 American Indian or Alaska Native
 Asian
 Black or African American
 Native Hawaiian or Other Pacific Islander
 White
 Other (please state):
reset

6a. Please specify.

7. What is your ethnicity?
 Hispanic or Latino
 Not Hispanic or Latino
reset

Alternative questions show if select "other" for question #5:

5. Country of residence:
 USA
 Other

5b. Please specify.

8. What is the highest level of education you have completed?

- Did not complete high school
- High school degree or equivalent (e.g. GED)
- Some college but not degree
- Associate degree (2-year college degree)
- Bachelor's degree (4-year college degree)
- Graduate degree (completed graduate school after a 4-year college degree)

[reset](#)

9. Were you employed right before the coronavirus pandemic?

- Yes
- No

[reset](#)

9a. If yes, did you work part-time or full-time?

- Part-time
- Full-time

[reset](#)

9b. Did you work primarily at home or outside of the home before the coronavirus pandemic?

- Worked outside the home
- Worked at home

[reset](#)

9c. What is your current employment status DURING the coronavirus pandemic?

- Still working
- Laid off
- Furloughed
- Other

[reset](#)

9d. Please specify.

10. Are you currently enrolled in school/college?

- Yes
- No

[reset](#)

10a. If yes, part-time or full-time?

- Part-time
- Full-time

[reset](#)

Alternative Response Options show if respond "no" to #9:

9. Were you employed right before the coronavirus pandemic?

- Yes
- No

[reset](#)

9a. If you were not employed right before the coronavirus pandemic, what was the reason?

- Not employed by choice
- Not employed due to disability
- Not employed while looking for another job
- Other

[reset](#)

9a. Please specify.

[Expand](#)

11. Do you have other family members with NF?

- Yes
- No
- Not sure

reset

NF1 Specific Questions:

12. Select your primary diagnosis:

- NF1
- NF2
- Schwannomatosis

reset

12a. Do you have optic pathway glioma (brain tumor involving the nerves of the eyes)?

- Yes
- No
- Unsure

reset

If yes, how much does your optic pathway glioma affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

reset

12b. Do you have cutaneous neurofibromas (tumors on or under the skin)?

- Yes
- No
- Unsure

reset

If yes, how much do your cutaneous (skin) neurofibromas affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

reset

12c. Do you have glomus tumors (tumors in the fingers or toes)?

- Yes
- No
- Unsure

reset

<p>If yes, how much do your glomus tumors (in your fingers and toes) affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12d. Do you have plexiform neurofibromas (tumors that grow along the nerves)?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your plexiform neurofibromas (nerve tumors) affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12e. Do you have scoliosis (curving of the spine)?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much does your scoliosis affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12f. Do you have other orthopedic problems (curving of the leg bones, leg length discrepancy, etc)</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>

<p>If yes, how much do your orthopedic problems affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12g. Do you have learning disabilities and/or attention problems?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your learning disabilities or attention problems affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12h. Do you have mental health difficulties (such as anxiety, depression, etc. unrelated to the coronavirus pandemic and quarantine)?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your mental health difficulties affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12i. Do you have social skills difficulties?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>

<p>If yes, how much do your social skills difficulties affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12j. Do you have vision problems?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your vision problems affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12k. Do you have any hearing problems?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your hearing problems affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12l. Do you have café au lait spots?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>

If yes, how much do your café au lait spots affect your everyday life?	<input type="radio"/> Does not affect my everyday life at all <input type="radio"/> Affects my everyday life a little <input type="radio"/> Affects my everyday life somewhat <input type="radio"/> Affects my everyday life a lot reset
12m. Do you have short stature?	<input checked="" type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unsure reset
If yes, how much does your short stature affect your everyday life?	<input type="radio"/> Does not affect my everyday life at all <input type="radio"/> Affects my everyday life a little <input type="radio"/> Affects my everyday life somewhat <input type="radio"/> Affects my everyday life a lot reset
12n. Do you have malignant peripheral nerve sheath tumors?	<input checked="" type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unsure reset
If yes, how much do your malignant peripheral nerve sheath tumors affect your everyday life?	<input type="radio"/> Does not affect my everyday life at all <input type="radio"/> Affects my everyday life a little <input type="radio"/> Affects my everyday life somewhat <input type="radio"/> Affects my everyday life a lot reset
12o. Do you have seizures?	<input checked="" type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unsure reset

<p>If yes, how much do your seizures affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12p. Do you have headaches?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your headaches affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12q. Do you have tumor-related pain?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much does your tumor-related affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12r. Do you have other pain (not related to tumors)?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>

If yes, how much does your other pain (not related to your tumors) affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

[reset](#)

12s. Do you have other complications or concerns?

- Yes
- No
- Unsure

[reset](#)

If yes, please list:

[Expand](#)

If yes, how much do your other complications affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

[reset](#)

13. Check the one statement that best describes how much all of your NF symptoms affect your everyday life:

- My NF symptoms do not affect my everyday life at all
- My NF symptoms affect my everyday life a little (mild degree)
- My NF symptoms affect my everyday life somewhat (moderate degree)
- My NF symptoms affect my everyday life a lot (severe degree)

[reset](#)

14. In the past year, how often did you visit a doctor for your NF or a symptom related to NF?

- Not at all in the past year
- 1 time in the past year
- 2-3 times in the past year
- 4-5 times the past year
- More than 5 times the past year

[reset](#)

15. How far are you from the nearest NF clinic?

- Less than 1 hour
- 1 hour
- 2 hours
- 3 hours
- 4 hours
- More than 5 hours
- I don't know

reset

16. Have you ever been in a drug clinical trial for NF?

- Yes
- No
- Not sure

reset

17. Have you ever been in a psychosocial clinical trial for NF?

- Yes
- No
- Not sure

reset

Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.

Submit

11. Do you have other family members with NF?

- Yes
 No
 Not sure

reset

NF2 Specific Questions:

12. Select your primary diagnosis:

- NF1
 NF2
 Schwannomatosis

reset

12a. Do you have vestibular schwannoma/acoustic neuroma (brain tumors on the hearing/balance nerve)?

- Yes
 No
 Unsure

reset

If yes, how much does your vestibular schwannoma(s) affect your everyday life?

- Does not affect my everyday life at all
 Affects my everyday life a little
 Affects my everyday life somewhat
 Affects my everyday life a lot

reset

12b. Do you have meningiomas (tumors) in the brain?

- Yes
 No
 Unsure

reset

If yes, how much does your meningioma(s) affect your everyday life?

- Does not affect my everyday life at all
 Affects my everyday life a little
 Affects my everyday life somewhat
 Affects my everyday life a lot

reset

12c. Do you have tumors involving the spinal cord or spinal nerves (including ependymomas, spinal meningiomas, or spinal schwannomas)?

- Yes
 No
 Unsure

reset

<p>If yes, how much does your spine tumor(s) affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12d. Do you have hearing problems?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your hearing problems affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12e. Do you have tinnitus (ringing of the ears)?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much does your tinnitus affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12f. Do you have balance problems?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>

<p>If yes, how much do your balance problems affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12g. Do you have vision problems?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your vision problems affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12h. Do you have facial weakness/facial nerve damage?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your facial weakness affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12i. Do you have speech or swallowing difficulties?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>

<p>If yes, how much do your speech or swallowing difficulties affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12j. Do you have pain?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much does pain affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12k. Do you have muscle wasting?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Not sure</p> <p>reset</p>
<p>If yes, how much does muscle wasting affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12l. Do you have mental health difficulties (such as anxiety, depression, etc. unrelated to the coronavirus pandemic and quarantine)?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>

If yes, how much do your mental health difficulties affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

[reset](#)

12m. Do you have social skills difficulties?

- Yes
- No
- Other

[reset](#)

If yes, how much do your social skills difficulties affect your everyday life?

- Does not affect my everyday life at all
- Affects my everyday life a little
- Affects my everyday life somewhat
- Affects my everyday life a lot

[reset](#)

12n. Do you have other complications or concerns?

- Yes
- No
- Unsure

[reset](#)

If yes, please list:

[Expand](#)

13. Check the one statement that best describes how much all of your NF symptoms affect your everyday life:

- My NF symptoms do not affect my everyday life at all
- My NF symptoms affect my everyday life a little (mild degree)
- My NF symptoms affect my everyday life somewhat (moderate degree)
- My NF symptoms affect my everyday life a lot (severe degree)

[reset](#)

14. In the past year, how often did you visit a doctor for your NF or a symptom related to NF?	<input type="radio"/> Not at all in the past year <input type="radio"/> 1 time in the past year <input type="radio"/> 2-3 times in the past year <input type="radio"/> 4-5 times the past year <input type="radio"/> More than 5 times the past year reset
15. How far are you from the nearest NF clinic?	<input type="radio"/> Less than 1 hour <input type="radio"/> 1 hour <input type="radio"/> 2 hours <input type="radio"/> 3 hours <input type="radio"/> 4 hours <input type="radio"/> More than 5 hours <input type="radio"/> I don't know reset
16. Have you ever been in a drug clinical trial for NF?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not sure reset
17. Have you ever been in a psychosocial clinical trial for NF?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not sure reset
Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.	
<div style="text-align: center;"><input type="button" value="Submit"/></div>	

11. Do you have other family members with NF?

- Yes
 No
 Not sure

reset

Schwannomatosis Specific Questions:

12. Select your primary diagnosis:

- NF1
 NF2
 Schwannomatosis

reset

12a. Do you have brain tumors (including vestibular schwannomas/acoustic neuromas, meningiomas, and cranial nerve schwannomas)?

- Yes
 No
 Unsure

reset

If yes, how much does your brain tumor(s) affect your everyday life?

- Does not affect my everyday life at all
 Affects my everyday life a little
 Affects my everyday life somewhat
 Affects my everyday life a lot

reset

12b. Do you have spinal schwannomas (tumors in or near your spine)?

- Yes
 No
 Unsure

reset

If yes, how much does your spine tumor(s) affect your everyday life?

- Does not affect my everyday life at all
 Affects my everyday life a little
 Affects my everyday life somewhat
 Affects my everyday life a lot

reset

12c. Do you have other schwannomas (tumors in the rest of your body, including your neck, chest, abdomen, pelvis, or limbs)

- Yes
 No
 Unsure

reset

<p>If yes, how much do your hearing problems affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12d. Do you have problems with physical functioning (such as difficulty walking, sitting, or grasping objects)?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your problems with physical functioning affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12e. Do you have pain?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much does pain affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12f. Do you have problems sleeping?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>

<p>If yes, how much do problems sleeping affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12g. Do you have mental health difficulties (such as anxiety, depression, etc. unrelated to the coronavirus pandemic and quarantine)?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, how much do your mental health difficulties affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12h. Do you have social skills difficulties?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Other</p> <p>reset</p>
<p>If yes, how much do your social skills difficulties affect your everyday life?</p>	<p><input type="radio"/> Does not affect my everyday life at all</p> <p><input type="radio"/> Affects my everyday life a little</p> <p><input type="radio"/> Affects my everyday life somewhat</p> <p><input type="radio"/> Affects my everyday life a lot</p> <p>reset</p>
<p>12i. Do you have other complications or concerns?</p>	<p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Unsure</p> <p>reset</p>
<p>If yes, please list:</p>	<div data-bbox="927 1728 1390 1877" style="border: 1px solid black; height: 70px;"></div> <p>Expand</p>

13. Check the one statement that best describes how much all of your NF symptoms affect your everyday life:

- My NF symptoms do not affect my everyday life at all
- My NF symptoms affect my everyday life a little (mild degree)
- My NF symptoms affect my everyday life somewhat (moderate degree)
- My NF symptoms affect my everyday life a lot (severe degree)

[reset](#)

14. In the past year, how often did you visit a doctor for your NF or a symptom related to NF?

- Not at all in the past year
- 1 time in the past year
- 2-3 times in the past year
- 4-5 times the past year
- More than 5 times the past year

[reset](#)

15. How far are you from the nearest NF clinic?

- Less than 1 hour
- 1 hour
- 2 hours
- 3 hours
- 4 hours
- More than 5 hours
- I don't know

[reset](#)

16. Have you ever been in a drug clinical trial for NF?

- Yes
- No
- Not sure

[reset](#)

17. Have you ever been in a psychosocial clinical trial for NF?

- Yes
- No
- Not sure

[reset](#)

Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.

Submit



Specific Questions about Psychosocial Trials

Your answers to the questions below will help us plan psychosocial trials based on your preferences and concerns so that the studies will be more meaningful to you.

18. What are the BEST ways for you to learn about psychosocial clinical trials and research opportunities in NF? (Check up to SIX)

- My NF doctor or nurse
- My regular doctor or nurse
- Other specialist doctor
- Information posted in my NF clinic
- Information from NF Foundation websites
- Children's Tumor Foundation registry
- Clinicaltrials.gov
- Social media posts
- Other NF patients
- Internet searches
- Email listserv
- Other, please specify:

18a. Other, please specify:

Expand

19. What information is the MOST important to you when deciding whether to participate in a psychosocial clinical trial? (Check up to SIX)

- Scientific background of the study
- How the study may help me
- If the study may help others in the future
- Information about the study procedures
- Number of clinic visits required
- Patient involvement in the design of the trial
- Time commitment (in clinic or at home)
- Time away from work
- Accessibility (for example, how much travel is involved)
- Compensation (payment for participating in a study)
- Security of my personal information
- Experience of the participants previously in the study
- Reimbursement of expenses (for example: travel)
- Other, please specify: _____
- None of the above

19a. Other, please specify:

Expand

20. What are the MAIN reasons why you would take part in a psychosocial clinical trial? (Check up to THREE)

- To improve my health and well-being
- To meet and be cared for by NF experts
- To try new interventions for NF symptoms
- To help others with NF based on what is learned in the study
- To meet other patients with NF
- Other, please specify:
- None of the above

20a. Other, please specify:

Expand

21. What are the MAIN reasons why you would NOT participate in a psychosocial clinical trial even if you were eligible for it? (Check up to SIX)

- Time commitment in clinic
- Time commitment at home
- Time away from work or school
- Distance to the clinic/research center if need to attend in person
- Lack of experience with computers if need to do the study online (for example: using videochat)
- Costs
- Not enough compensation (the amount of money given as a thank you to participate)
- Concern about the privacy and security of my personal information
- Intervention is not yet proven to be effective in NF
- I think my NF symptoms are not severe enough
- I think my NF symptoms are too severe
- I don't have a mobile phone
- I don't have a computer
- I am worried about participating in a psychosocial clinical trial
- I don't think a psychosocial trial would help me
- I don't think I need to participate in a psychosocial trial
- Other, please specify:
- None of the above

21a. Other, please specify:

Expand

<p>22. What kind of computer or mobile device do you have regular access to? (Check all that apply):</p>	<p><input type="checkbox"/> desktop or laptop computer (PC or Mac)</p> <p><input type="checkbox"/> smartphone (like an iPhone or Android)</p> <p><input type="checkbox"/> regular cell phone</p> <p><input type="checkbox"/> electronic tablet (like an iPad or Microsoft)</p> <p><input type="checkbox"/> none of the above</p>
<p>23. Does your computer have a camera in it or do you own a separate webcam (for doing video chats)?</p>	<p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Not sure</p> <p style="text-align: right;">reset</p>
<p>24. Do you have access to the internet?</p>	<p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Not sure</p> <p style="text-align: right;">reset</p>
<p>25. Do you require captioning/CART (Communication Access Real-time Translation)?</p>	<p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Not sure</p> <p style="text-align: right;">reset</p>
<p>26. Do you have concerns about the privacy of your information?</p>	<p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Not sure</p> <p style="text-align: right;">reset</p>
<p>Not at all A little Somewhat Fairly A lot</p>	
<p>27. Would getting some compensation to pay for travel, parking, or meals make you more likely to participate in a psychosocial trial?</p>	<p><input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/></p> <p style="text-align: right;">reset</p>
<p>28. Would getting a small compensation (such as \$20 per visit) as a thank you make you more likely to participate in a psychosocial trial?</p>	<p><input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/></p> <p style="text-align: right;">reset</p>
<p>A RANDOMIZED CONTROLLED TRIAL is a clinical trial where participants are randomized (like flipping a coin) between one intervention and no intervention (control group) or between two different types of interventions. This type of trial is important to prove a new intervention is effective.</p>	

29. Would you participate in a psychosocial RANDOMIZED CONTROLLED TRIAL if you might not get the intervention?

Yes
 No
 Not sure

[reset](#)

30. Would you participate in a psychosocial RANDOMIZED CONTROLLED TRIAL if you might not know which intervention you will be getting?

Yes
 No
 Not sure

[reset](#)

31. Would you participate in a psychosocial RANDOMIZED CONTROLLED TRIAL if you could get the intervention after a short waiting period?

Yes
 No
 Not sure

[reset](#)

Not at all A little Somewhat Fairly Very

32. How important is it for participants to receive results of the study?

[reset](#)

33. What are the BEST ways to communicate the results of a psychosocial trial to the participants? (Choose up to FOUR)

(One selection allowed per column)

	First choice	Second choice	Third choice	Fourth choice
Letter summarizing the results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Email summarizing the results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Summary article in NF foundation newsletters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Summary article posted on NF foundation websites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Copy of the scientific article	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, please specify:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[reset](#)

34. How would you PREFER that the study investigators communicate with patients while at home during a psychosocial trial? Please rank the following from first to third.

(One selection allowed per column)

	First choice	Second choice	Third choice
Text messages	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emails	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phone Calls	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, please specify:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[reset](#)

35. What would you be willing to do to help clinical researchers plan specific psychosocial trials to make them more relevant to patients with NF? (Choose up to FOUR)

(One selection allowed per column)	First choice	Second choice	Third choice	Fourth choice
Complete surveys like this (both before and after the trial)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Participate in focus groups in person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Participate in interviews in person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Participate in focus groups over video on the computer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Participate in individual interviews over the phone or video on the computer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Have patient representatives involved in the design of the trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Other, please specify:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.				
<input type="button" value="Submit"/>				

Resize font:  

Specific Questions about Psychosocial Trials Continued

Not at all A little Some Pretty much A lot

36. How much does NF affect your PHYSICAL well-being?

[reset](#)

Not at all A little Some Pretty much A lot

37. How much does NF affect your EMOTIONAL well-being?

[reset](#)

Not at all A little Some Pretty much A lot

38. How much does NF affect your SOCIAL well-being?

[reset](#)

Not at all A little Some Pretty much A lot N/A

39. How much does NF affect your functioning at WORK or SCHOOL?

[reset](#)

Not at all A little Some Pretty much A lot

40. How much does NF affect your functioning at HOME?

[reset](#)

Please answer questions 41 - 43 about your mental health (UNRELATED TO THE CORONAVIRUS PANDEMIC AND QUARANTINE).

41. Have you been diagnosed with anxiety, depression, or other mental health problems?

Yes
 No
 Not sure

[reset](#)

41a. If you have not been diagnosed, do you think you have anxiety, depression, or other mental health problems?

Yes
 No
 Not sure

[reset](#)

42. Have you taken medicine recently for anxiety, depression, or other mental health problems?

Yes
 No

[reset](#)

43. Have you seen a mental health professional recently for anxiety, depression, or other mental health problems?

Yes
 No

[reset](#)

44. If you experience NF-related pain, please check the ways you currently treat your pain. (Check all that apply)

- I do not have NF related pain
- I do nothing to treat my pain
- I take over the counter medicine (for example, Tylenol, motrin)
- I take prescription medicine (for example, Neurontin or Oxycodone)
- I do alternative therapies (for example, acupuncture or biofeedback)
- I do talk therapy (for example, cognitive behavioral therapy)
- Other (please specify):

44a. Other, please specify:

Expand

To help us better understand the psychosocial challenges that children with NF might face growing up, please answer the following questions:

45. Did you ever experience any learning difficulties when you were growing up?

- Yes
- No
- Don't remember

reset

45a. If yes, about what age were you when you first noticed you had learning difficulties?

45b. If yes, did you receive any intervention or assistance with these learning difficulties?

- Yes
- No
- Not sure

reset

46. Did you ever experience any difficulties with social interactions with peers (bullying, limited friends, etc.) when you were growing up?

- Yes
- No
- Don't remember

reset

46a. If yes, about what age were you when you first noticed you had these social difficulties?

<p>46b. If yes, did you receive any intervention or assistance with these social difficulties?</p>	<p> <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not sure </p> <p style="text-align: right;">reset</p>
<p>47. Did you ever experience any difficulties with your mood (anxiety, depression, etc.) when you were growing up?</p>	<p> <input checked="" type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't remember </p> <p style="text-align: right;">reset</p>
<p>47a. If yes, about what age were you when you first noticed you had these mood difficulties?</p>	<input style="width: 150px; height: 20px;" type="text"/>
<p>47b. If yes, did you receive any intervention or assistance with these mood difficulties?</p>	<p> <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not sure </p> <p style="text-align: right;">reset</p>
<p>48. What types of psychosocial trials would you be MOST interested in participating in? (Check up to SIX)</p>	<p> <input type="checkbox"/> To help increase my social interaction with others <input type="checkbox"/> To help me with anxiety <input type="checkbox"/> To help me with depression <input type="checkbox"/> To learn ways to cope with pain <input type="checkbox"/> To learn ways to cope with daily stress <input type="checkbox"/> To help me cope with trauma related to NF (for example: surgery, medical procedures) <input type="checkbox"/> To help develop a healthier lifestyle (like nutrition, physical activity) <input type="checkbox"/> To help me with family planning issues <input type="checkbox"/> To help me with parenting issues (with or without a child who has NF) <input type="checkbox"/> To cope with current or increasing physical difficulties from NF <input type="checkbox"/> To help me reach my full potential <input type="checkbox"/> To help me with cognitive and learning difficulties <input checked="" type="checkbox"/> Other (please specify): <input type="checkbox"/> None of the above </p>

48a. Other (please specify):	<div style="border: 1px solid gray; height: 60px; width: 100%;"></div> <p style="text-align: right; font-size: small;">Expand</p>
49. How willing would you be to participate in a psychosocial trial if it targeted an important concern that you have about your NF?	<ul style="list-style-type: none"><input type="radio"/> I definitely would want to participate<input type="radio"/> I probably would want to participate<input type="radio"/> I might want to participate<input checked="" type="radio"/> I'm not sure<input type="radio"/> I might not want to participate<input type="radio"/> I probably would not want to participate<input type="radio"/> I definitely would not want to participate <p style="text-align: right; font-size: small;">reset</p>
49a. If you do not think you would participate in a psychosocial trial, what are the reasons why you would not want to participate? (open-ended)	<div style="border: 1px solid gray; height: 60px; width: 100%;"></div> <p style="text-align: right; font-size: small;">Expand</p>
50. What would you be willing to do to participate in a psychosocial trial? (Check ALL that apply)	<ul style="list-style-type: none"><input type="checkbox"/> Come into the nearest NF clinic 2 to 4 times a month for several months to participate in most of the study in person<input type="checkbox"/> Combination of coming in to the nearest NF clinic (1 to 2 times over the course of a 6 months study) but doing most of the program from home (using secure videochats, emails, videos)<input type="checkbox"/> Not come into the clinic at all and do all of the program from home on the computer (use secure videochats, emails, videos, internet support group)<input checked="" type="checkbox"/> Other (please specify):
50a. Other, please specify:	<div style="border: 1px solid gray; height: 60px; width: 100%;"></div> <p style="text-align: right; font-size: small;">Expand</p>

Text box appears when participants select "I'm not sure" or any of the options below it.

51. What type of program would you MOST prefer? (Check up to TWO)

- Individual sessions led by a clinician
- Group sessions led by a clinician
- Group sessions led by a trained peer facilitator
- Combination of group and individual sessions led by a clinician

52. What time of day would you MOST prefer to do the sessions for the psychosocial trial?

(One selection allowed per column)

	First choice	Second choice	Third choice	Fourth choice
Weekdays early in the evening (5 pm - 7 pm)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Weekdays later in the evening (7 pm - 9 pm)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Weekdays during lunch time (11 am - 2 pm)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Weekday mornings (9 am - 11 am)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Weekday afternoons (2 pm - 5 pm)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Weekends mornings (9 am - 12 pm)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Weekends afternoons (12 pm - 4 pm)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Other suggestions:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset

53. What outcomes would be MOST important to measure in a psychosocial trial? (Check up to SEVEN)

- Improvement in symptoms of anxiety
- Improvement in symptoms of depression
- Less symptoms of stress
- Improved coping skills
- Better self-esteem
- How much my pain hurts
- How much pain interferes with my daily activities
- Greater involvement in social activities
- Improved interpersonal relationships
- Less feelings of loneliness and social isolation
- Improved ability to manage NF symptoms
- Better physical functioning
- Improved cognitive and learning skills
- Improved performance at work or school
- Better overall quality of life
- Other (please specify):

53a. Other, please specify:

[Expand](#)

54. How would you PREFER that we administer questionnaires to assess changes from participating in psychosocial trials?

	Not at all	A little	Some	Pretty much	A lot
Online questionnaires completed on the computer from your home	<input type="radio"/>				
					reset
Online questionnaires completed on your mobile phone	<input type="radio"/>				
					reset
Paper and pencil questionnaires mailed to you at home	<input type="radio"/>				
					reset

<p>Paper and pencil questionnaires completed in person at a medical clinic</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>Questions completed in an interview over the phone</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>Questions completed in an interview in person at a medical clinic</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>Questionnaires completed on a computer or mobile tablet in person at a medical clinic</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>55. In addition to questionnaires, to what extent would you be willing to also use direct objective measures to assess change, such as activity trackers (like a Fit Bit), physiological measures (like heart rate), or stress biomarkers (like from saliva) in psychosocial trials?</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<p>Very willing</p> <p>Somewhat willing</p> <p>Not very willing</p> <p>Not at all willing</p>	reset
<p>56. Please tell us if there is anything else you would like us to know about how NF affects your social and emotional functioning.</p>	<div style="border: 1px solid #ccc; height: 70px;"></div>					Expand
<p>57. Please tell us if there is anything else you would like us to know to help us plan psychosocial intervention trials for people with NF1.</p>	<div style="border: 1px solid #ccc; height: 70px;"></div>					Expand
<p>Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.</p>						
<div style="border: 1px solid #ccc; padding: 5px; display: inline-block;"> <p>Submit</p> </div>						

Impact of Coronavirus

Please answer the following questions related to the **coronavirus** (also called **COVID-19**) pandemic:

A. During the worst of the coronavirus pandemic in your area, how worried were you about:

	Not at all	Slightly	Moderately	Very	Extremely
1. being infected with coronavirus?	<input type="radio"/>				
					reset
2. ... friends or family being infected with coronavirus?	<input type="radio"/>				
					reset
3. ... your physical health being influenced by coronavirus?	<input type="radio"/>				
					reset
4. ... your emotional health being influenced by coronavirus?	<input type="radio"/>				
					reset
	Not at all	Slightly	Moderately	Very	Extremely
B. How stressful has the coronavirus pandemic been for you?	<input type="radio"/>				
					reset

Which of the following events have you experienced as a result of the coronavirus pandemic? (For questions about coronavirus illness, please include instances of both suspected and confirmed cases).

C. (Select all that apply)

- Unemployment of self
- Unemployment of spouse/partner
- Significant reduction in/loss of main source of income
- Loss of health insurance coverage
- Experienced difficulties registering for unemployment benefits
- Tried to register for unemployment benefits but did not qualify
- Exposed to coronavirus
- Fell ill with coronavirus
- Family member fell ill with coronavirus
- Caring for a family member with coronavirus
- Death of family member due to coronavirus
- Death of a close friend due to coronavirus
- Work in healthcare setting with coronavirus patients
- Unable to quarantine due to work deemed "essential"
- Live with "essential" worker at high risk of contracting coronavirus
- Other
- NONE OF THE ABOVE

Please specify:

Expand

D. Please answer the following questions about your NF care during the coronavirus pandemic:**1. Was an in-person doctor's appointment for your NF care cancelled or delayed because of the coronavirus pandemic?**

- Yes
 No

[reset](#)

If yes, how much did missing that in-person doctor's appointment concern you?	<input type="radio"/> Not at all <input type="radio"/> Slightly <input type="radio"/> Moderately <input type="radio"/> Very Much <input type="radio"/> Extremely	reset
2. Was an in-person treatment for your NF cancelled or delayed because of the coronavirus pandemic?	<input checked="" type="radio"/> Yes <input type="radio"/> No	reset
If yes, how much did missing that in-person treatment concern you?	<input type="radio"/> Not at all <input type="radio"/> Slightly <input type="radio"/> Moderately <input type="radio"/> Very Much <input type="radio"/> Extremely	reset
3. Did you use telehealth instead of an in-person doctor's appointment for your NF care because of the coronavirus pandemic?	<input checked="" type="radio"/> Yes <input type="radio"/> No	reset
If yes, how much did the telehealth appointment meet your needs?	<input type="radio"/> Not at all <input type="radio"/> Slightly <input type="radio"/> Moderately <input type="radio"/> Very Much <input type="radio"/> Extremely	reset
E. Please let us know any other ways the coronavirus pandemic and the stay-at-home order has affected you.	<div style="border: 1px solid black; height: 60px; width: 100%;"></div>	Expand
Please check to make sure you have completed all questions in this section that you would like to answer before clicking submit.		
<div style="border: 1px solid black; padding: 5px; display: inline-block;">Submit</div>		

Close survey

Thank you for taking the survey.

Have a nice day!